MEDICAL RIGHTS OF CHILDREN

Best Interests versus Parental Authority

Jillian Inouye
Betty Vitousek

To be a child is to be at risk, dependent, and without capacity or authority to decide what is best for oneself. To be an adult is to be a risk taker, independent, and with the capacity to authorize, to decide, to do what is best for oneself. To be an adult who is a parent is to be presumed in law to have the capacity, authority, and responsibility to determine and do what is good for one's children.1

Because of the relative helplessness and dependency of the young child, parents throughout history have had absolute authority over their children. They were presumed because of affectionate bond to act in the best interest of the child. However, the child now has rights, enforceable rights, which, at times, are in direct opposition to his parents' desires or demands.2 The Declaration of the Rights of the Child adopted by the United Nations in 1959 revealed principles set forth for a happy childhood. From this, a right to medical care was established to promote the full development of the child.3 In cases of medical treatment, physicians are also involved in decisionmaking regarding the interests of the minor child. Complicating this is the fact that while parents have direct responsibility for the health care of the child, the state also has a clear interest in the well-being of the child.4 Thus, the issue of child rights in the area of medical care often collides with parental rights, state interests and medical responsibilities. As certain elements of society gain rights, there is likely to be an attendant beveling of rights and privileges of others.5

Parental Rights and Authority
The law tends to favor parental authority and attempts to protect family privacy by safeguarding parental authority in child-rearing.6 The Supreme Court has established that the 14th Amendment protects the very nature of family life.7 The state further recognizes that with the rights are concomitant responsibilities and burdens of care that parents, and no other party, must shoulder. However, the laws regarding parental authority to consent to or withhold medical treatment are not clear cut.8

Difficulties exist regarding the best interest of the child and the preserving of parental authority. In the case of certain medical care and treatment, the physician and the courts also become involved. Traditionally, parents have had control over decisions in two major areas.9 One is their duty to make decisions on behalf of the child which include shelter, food, and medical care. They are authorized to raise children according to personal beliefs, preferences, and lifestyles—especially when a decision involves issues over which no societal consensus exists. The second area of parental control is their right to freedom from state interference. This right, which has been articulated in the Supreme Court, includes decisions related to educational and religious upbringing, and the right to raise children according to their own values. However, in life-and-death decisions,
non-treatment based on religious objections usually had not been upheld by the courts. These cases have dealt mainly with transfusions, and resulted in juvenile and domestic courts appointing a special guardian to administer the transfusion. The state's "neglect statutes" confer such power on the court when children are found to be neglected.

Child's Rights to Medical Care

Historically, unemancipated minors could not receive medical treatment without parental consent, but this perspective has recently been questioned by child liberators who want more decisionmaking powers given to the child. Because of medical decisions made by physicians, the concept of the child as a piece of property owned by parents is changing; the irrevocability of any parental right of decisionmaking is open to question even beyond those restricted to life-threatening areas. There now appears to be a state of flux in the law and a time of change in parental, as well as children's, rights in this area. Although it was not until the 1960s that child abuse and neglect laws were passed to protect children from their parents, new laws now permit the adolescent to assume responsibility for his own actions over the care of his body.

In terms of rights in the medical area, three relevant ones are: (1) The right of the child in experimental investigation; (2) the right of the child in receiving treatment without parental knowledge, and (3) the right of the child to receive medical care over parental objection. The "Mature Minor's Rule" represents a liberalizing trend in allowing minors to make decisions regarding medical care. It allows unemancipated minors, who have sufficient intelligence to understand the nature and consequence of the treatment, to give consent to medical care if such treatment is for their benefit. With respect to specific medical treatment, several changing rights for minors have been noted in various states and include: (1) The right of physicians to diagnose and treat venereal disease in minors without parental consent; (2) the right of adolescents to seek care for pregnancy and contraceptive services, and (3) the right of minors to receive treatment for drug abuse and emotional problems without parental consent.

Two recent decisions of the US Supreme Court—concerning abortion decisions and commitment to mental institutions—illustrate the difficulty in deciding "best interest" versus parental authority in the medical area. In Planned Parenthood v. Danforth, the Supreme Court held that Missouri's statute was unconstitutional because it provided parental veto of an abortion decision made by a pregnant minor. The other case dealt with parents' decision to commit their children to a mental institution. In this case, the court ruled that parents have the right and duty to seek and follow medical advice, and further stated that children, even in adolescence, are unable to make sound decisions. Both decisions resulted in the court attempting to define the family's and physician's roles in protecting the rights of children. However, the results were contradictory because instead of interpreting the Constitution, the court's ruling attempted to decide what was best for the country by determining what was best for the family.

Generally, most rights granted to minors in the medical area suggest that age requirements should be rejected in favor of competence of the minor. When competence is evidenced, he should have the legal right to decide without parental interference. Further, when there is a conflict of parental interest, parents should no longer be permitted to make decisions. Nowhere is there a more controversial issue than in the case of non-treatment for infants and incompetents. Until recently, the Quinlan case was the most important regarding the withdrawal of extraordinary treatment from a patient unable to make that decision. A similar case was that of Joseph Saikewicz (opinion of the Massachusetts Supreme Judicial Court, November 22, 1977), a 67-year-old profoundly retarded man who was institutionalized all his life and unable to communicate verbally. On April 19, 1976, he was diagnosed as suffering from a form of lethal leukemia. The treatment considered offered only a 30 to 50 percent chance of remission possibly lasting from 2 to 13 months and had numerous and dangerous side effects, which included pain, discomfort, anemia, hair loss, bone marrow depression, and, eventually, death. It would also require restraints and daily blood transfusions. Left untreated, he could be expected to live only several weeks. The institution petitioned the court for the appointment of a guardian ad litem to make necessary decisions concerning his care. Two physicians testified against treatment, with the judge concurring. There were no interested third parties since his only living relatives were not interested and did not want to be involved. An immediate appeal was taken. The court affirmed that decision on July 2, with a full opinion to follow. Joseph Saikewicz died on September 4 of bronchial pneumonia. In November 1977, after time to consider the issue carefully without necessity of rendering emergency treatment, the court issued its full opinion dealing with the issues of (1) the right of any person, competent or not, to decline potentially life-prolonging treatment; (2) the legal standards that control the decision as to whether potentially life-prolonging, but not life-saving,
treatment should be administered to an incompetent, and (3) the procedures that must be followed in arriving at that decision.\(^2^1\)

In general, the decision relates to the patient's right to human dignity and autonomy with the right to refuse life-sustaining treatment that would not cure or preserve life. The court also found that such decisions must be based on the doctrine of substituted judgement, or on an attempt to determine what the incompetent would do if he could make that choice for himself, rather than on what a majority of reasonable persons might do.\(^2^2\) Furthermore, the court firmly rejected the quality of life issues as a determinant in its decision and outrightly rejected the role of ethics committees as envisioned by the Quinlan court, except in an advisory role. It made clear that only judges should decide cases of life and death, with legal immunity.

The case of Joseph Saikewicz highlights several issues regarding the decision not to treat, or to discontinue treatment. These are (1) the right to informed consent; (2) the issue of quality of life versus the sanctity of life; (3) the definition of personhood or humanness, and (4) ordinary versus extraordinary methods of treatment. The severely-handicapped or defective infant is covered by the law, with the right to life and care; however, many still feel that his rights end when in conflict with that of parents, medicine, society, and his own potential for development.\(^2^3\) While policymakers have avoided the above issues, judges have been increasingly finding themselves in the role of decisionmakers. Rights and responsibilities of all parties are intertwined in these issues,\(^2^4\) and involve medical, legal, and ethical decisions.\(^2^5\) The above issues will be reviewed with particular reference to the defective infant, or one who cannot make his own decision.

The Right of Informed Consent. The right of informed consent is a legal right to make decisions after full explanation is given regarding the risks and limitations involved.\(^2^6\) It stems from the general right of "bodily/self-determination."\(^2^7\) However, with infants or incompetents, the law provides for the appointment of a guardian until they reach the age of majority. While adults have refused medical and life-prolonging treatment for themselves, with minors, a parent's decision to refuse treatment is subject to review when physician and society disagree with that decision.\(^2^8\) Thus, there is a safeguard for minor's rights when there is conflict among the parties involved.

Quality of Life versus Sanctity of Life. Ethics in the medical profession lead physicians to attempt to treat even when there is little hope. This role of medicine is reinforced by society's recognition of the "inestimable worth of a single life."\(^2^9\) Those who believe this have an easy time making decisions. Yet, others feel that decisions need to be based on circumstances of each case rather than on a dogmatic approach.\(^3^0\) One proposed argument for withholding care is that the defective infant is not a person, or that he lacks the possibility of quality in life. People have even proposed a formula for deducing quality of life.\(^3^1\) An early legal definition rules that all human offspring are persons with rights—the only exception being evidence to show beyond a reasonable doubt that certain offspring would never possess minimal properties that a reasonable person ordinarily associates with human personality.\(^3^2\)

Others, however, feel that it is dangerous for decisions to be based on the quality of life since society then becomes the judge in making decisions—with the high possibility for abuse—when one is useless, non-productive, or too costly to protect with full legal and moral rights.\(^3^3\) These judgements about quality of life are philosophical and should never be followed because of bias on the part of guardians or physicians, as well as the obvious problems of egocentricity.\(^3^4\)

Personhood or Humanness. Relative to the issue of quality of life is that of personhood or humanness. Several authors have proposed criteria or minimal standards by which to judge the quality of life.\(^3^5\) These are sometimes based on intelligence and potential contribution to society. To be a person one must have self-consciousness, rational ability, neocortical function, happiness, capacity to love and be loved, potential for independence, capacity to understand, and the ability to plan for the future. The same authors (see footnote 35) who propose the above criteria also argue that the defective infant is not a person and thus not entitled to rights and protection of the Constitution and other laws. But, it is obvious that the definition of humanness is open to much abuse as was evident in Nazi Germany. Legal precedent, therefore, supports the existence of humanness following a live birth; the infant is a person with fundamental rights. The law generally presumes that personhood exists with entitlement to the usual legal protection regardless of the physical and mental characteristics of the infant.\(^3^6\)

Ordinary versus Extraordinary Care. Until recently, infants with severe defects died of natural causes. It was common for parents to request and physicians to agree not to treat such infants. Although non-treatment occurred throughout history, it has only recently been openly acknowledged and challenged.\(^3^7\) The distinction between ordinary and extraordinary care has not been recognized in cases on statutory laws nor adequately analyzed in the legal literature.\(^3^8\) According to one author, "ordinary" means are all medicine, treatment, and operations which offer a reasonable hope of benefit and which
can be obtained and used without excessive expense, pain, or other inconveniences. "Extraordinary" means are all medicine, treatment, and operations which cannot be obtained or used without excessive expense, pain or other inconveniences, or which, if used, would not offer a reasonable hope of benefit. According to this distinction, ordinary care must be maintained, while extraordinary treatment is optional. This distinction, however, is not too clear since a reasonable hope of benefit can change from time to time and from society to society and, thus, the distinction can be criticized as being too vague and incapable of definition.

State Intervention
The history of state intervention in infant affairs has traditionally been explained by the doctrine of parens patriae, or "father of his country." This was related to the King's ability to protect lunatics because they couldn't take care of themselves, and also applied to children. This later extended to the state's right to intervene in child rearing based on the purpose of protecting all who could not protect themselves and to compel minors and their parents to act in ways most beneficial to society. More recently, the state has been considered a guardian of society's basic values and one of the values protected by the state is the sanctity of life.

State intervention has focused on three major issues regarding the rights of the child. The first deals with the area of conflict between parental rights and the rights of the child and how such conflicts can be resolved in the best interest of the child. The second is concerned with how to determine the developmental issues or the ways in which children are different from adults. The final issue involves division of responsibility between the family and society in regard to children's socialization and welfare. In the area of requiring medical treatment over parental objection, the collision of parental and child rights is at the forefront. The state must decide if its obligation to insure the child's well-being outweighs the desires and rights of the parents. Goldstein, Freud, and Solnit provide guidelines to justify state intervention. They state that it would be justified "to provide any proven, nonexperimental medical procedure when its denial would mean death for a child who otherwise would have an opportunity for a life worth living or a life of relatively normal healthy growth." Thus, the state would need to establish that (1) the medical profession is in agreement about what non-experimental treatment is appropriate for the child; (2) the denial of the treatment would mean death for the child, and (3) the expected outcome of that treatment is what society agrees to be the right of any child, i.e., a chance for normal healthy growth or a life worth living. It is the third guideline that has stirred the most controversy. The life-worth-living is a highly subjective, ethical concept with no clear consensus from society. Many feel this gives leeway for parents and parental beliefs, since parents cannot make wrong decisions if there is no way of knowing the right answer. The burden, then, remains on the state to establish wrong. Others have avoided the issue of a life-worth-living and proposed decisions based on a medical feasibility model in which treatment is only infeasible when death is imminent and when proposed treatment cannot restore consciousness. This process of legal solution would utilize physicians as medical experts, parents as primary decisionmakers, and judicial review as a way of protecting the state's interests.

In conclusion, when conflict between children's rights and parental authority occurs, the legal system determines priorities with primary emphasis given to the best interest of the child over parental or state's rights. When decisions on life or death are to be made, the courts will always reserve the right to overrule parents as decisionmakers. While the question of excessive burden—such as financial and psychological strain—on the parent usually is not an issue, it may, in certain, limited circumstances, be ethical to consider grave burdens on parents as a justification for non-treatment. The issue of criminality for non-treatment has not been approached in this article, but some authors have argued that death by non-treatment violates criminal statutes, including child abuse and homicide laws and that parents as well as physicians may be found guilty of homicide by omission. Others maintain, however, that the more important ethical question is the one of "ordinary" versus "extraordinary" measures of treatment and advocate a change in legal policy rather than private individual action as a solution to the non-treatment dilemma.

"The absence of due process for the infant is all the more striking given the emotional circumstances of the parental decision and lack of publicly certified guidelines or criteria for withholding care . . . , interests other than infants can dominate, and in such arbitrary and unjustified decisions, killings can and have occurred." Since there is no clear consensus as to what is the good life for a child or a hierarchy of values by which to make decisions, it can only be hoped that when decisions concerning children are made in the judicial process, that the child, the family, the state, and qualified professionals are involved.
Footnotes

5Vitousek, op. cit.
7Ibid.
11Ibid.
14Annas, op. cit.
15Seagull, op. cit.
18Annas, op. cit.
19Ibid.

20Mnookin, op. cit.
22Ibid.
27Sargeant, op. cit.
29Sargeant, op. cit.
30Shaw, A. “Dilemmas,” op. cit.
32Robertson, op. cit.
34Robertson, op. cit.
39Robertson, op. cit.
40Macmillan, op. cit.
41Ibid.
43Macmillan, op. cit.
45Goldstein, et. al, op. cit.
46Ibid.
47Macmillan, op. cit.
48Ibid.
49Sargeant, op. cit.
50Robertson and Robertson & Fost, op. cit.
51Macmillan, op. cit.
52Robertson, op. cit.

Jillian Inouye is Doctoral Candidate, Developmental Psychology, University of Hawaii at Mānoa. Besides her interest in children’s rights, she is also concerned with issues related to ethnic differences and to early indicators of developmental abnormalities.

Betty Vitousek is Senior Judge, Family Court, State of Hawaii. She has served as Hawaii’s delegate to the White House Conference on Children (1970), President of the Association of Family Conciliation Courts (1974) and Member of the Committee on Children’s Rights, Family Law Section, American Bar Association (1974).